

Management committee

Tuesday 19th March 2023 10am-12pm

Attendees: Anjali Batish, Fiona Davey, Mike Grocott, Alan Jackson, Steve Wootton

Apologies: Vicky Coyle

Item	Actions	Lead	Deadline
Minutes of the last meeting	The minutes of the last meeting were accepted.		
	Review of actions from previous meeting Integrated Care Boards SAW has initiated discussion with Derek Sandeman regarding the ICBs and how we could link with them. Action: report back at next meeting	SAW	16/4/24
	Phase 3 report SAW is working to edit the current content for the report. SA has submitted a report from the perspective of Chair which needs to be edited and condensed. The full version could be published as a separate statement. Actions: MG to provide quotes on behalf of Southampton BRC	MG	16/4/24
	Ask SA for further insight/quotes on Collaboration activities	SAW/FD	30/4/24
	NIHR Comms AB spoke to Godwin and confirmed NIHR supported with WCRF Cancer Prevention Action Week on their X account and will continue to support when requested.		
Outstanding tasks	PPIE applicants in funding process AB has explored with other TRCs about PPIE involvement. They have had PPIE as co-applicants in studies but not leading studies themselves. Action: SAW to speak with CCF	SAW	30/4/24
	Succession planning VC is leading on refining the succession planning document and seeking further input from Executive Committee.		
	Membership one-pager SAW/AAJ to speak after this meeting and will start to draft the requirements and challenges facing the Collaboration		

	<p>with membership and charitable contributions.</p> <p>Nutrition Society SIG</p> <p>Actions:</p> <p>SAW to draft a one sider laying out ambition for SIG to recruit members.</p> <p>Arrange meeting for the core group before the end of April</p> <p>Draft communications for signed-up members to update on status</p>	<p>SAW</p> <p>FD</p> <p>SAW/FD</p>	<p>31/3/24</p> <p>31/3/24</p> <p>16/4/24</p>
PPIE panel	<p>The PPIE panel has continued to meet to plan its projects and agree its focus.</p> <p>The PPIE panel requires a chair and we hope that someone in the group wants to take on this role.</p> <p>Information provision</p> <p>The concerns shared are around the advice provided to patients, and that typically nutritional information given is more relevant to traditional north European/Caucasian dietary patterns, and do not meet the needs of a diverse population or accommodate inequities that might exist. They support the objective of providing better advice that is relatable across the population, and ensuring it is up to date. FD has identified a potential funding opportunity from MSD (Merck, in other countries) which has grant funding available to support projects in innovative methods of community engagement and addressing inequities.</p> <p>The panel also recognised the need for access to advice (i.e. through the FAQs) but are aware that there are many sources of advice published without people being aware of how secure the advice is.</p> <p>EDI</p> <p>With the panel's interest in ensuring dietary information is culturally representative and appropriate, there is a need to engage with dietetic/nutrition associations from the countries of reference for guidance on what advice is normally given.</p> <p>Consideration also needs to be given from a research perspective that typically data is sourced from Western Europe or North America.</p> <p>We will work with the PPIE panel to understand and articulate their felt needs which will enable the research community (through the Inclusivity Interest Group) to address these unmet needs through research.</p> <p>It was confirmed that these issues are important for NIHR as a whole and it has an EDI strategy which is being implemented, but further detail is required. A suggestion</p>		

	<p>was made to offer NIHR a perspective based upon the experiences of the Collaboration. This could be discussed with the TRCs Collaborations Managers.</p> <p>Action: AB to inform the committee about relevant conversations within the NIHR</p> <p>Action: AAJ to produce one-sider to capture core points and need for further discussion within NIHR</p> <p>Action: FD to raise PPIE at the Collaborations Managers meeting for them to start the conversation back to their TRCs with reference to AAJ one-sider</p> <p>Action: SAW/MG to initiate conversations through EDI group at Southampton BRC</p> <p>Research priorities The panel is also interested in identifying research priorities from patient’s perspectives rather than from science/clinical perspectives. Whilst JLA identifies top line priorities, it ends up blunting specific details into more generic statements (I.e. what lifestyle changes could support me in my treatment?). How could we engage with them in a process to look at research priorities?</p> <p>Healthcare professionals The final area of interest was the advice given by doctors and how healthcare professionals speak to them about nutrition and ensuring that advice aligns with formal guidance.</p> <p>Funding requirements We need to raise the funds to enable them to do specific tasks aligning with their priorities.</p> <p>Sense About Science SAS is willing to partner with the PPIE group to put a research proposal together looking at communicating the guidance to the public or health professionals. The budget required for working with SAS was estimated at about £50-60k. This budget would also include SAS’ role in convening further public representatives along with experts in the field in stakeholder consultations.</p>	<p>AB</p> <p>AAJ</p> <p>FD</p> <p>SAW/MG</p>	<p>30/4/24</p> <p>22/4/24</p> <p>TBC</p> <p>30/4/24</p>
Charity working group	<p>The charities are meeting on 20-3-24. We are bringing the charities together to engage with the Collaboration as a collective group. About 7 or 8 are joining this working group, out of the 14 who participated in the workshop before Christmas.</p> <p>We will be seeking nominations for a chair for the group.</p>		

	<p>WCRF has expressed a potential interest in taking on this role, which is to be confirmed.</p> <p>Their interests are in the area of information provision. It is not clear whether information provided is available in accessible forms and whether it is evidence-based. They would like to produce an un-curated list of what the charities offer to patients/families/carers. We will map out what is available and where the gaps are.</p>		
Phase three report	<p>Actions: SAW to share SA's report/comments with AAJ. SAW to share first draft next week.</p>	SAW	26/3/24
Work streams lead meeting	<p>Feedback from the Executive Committee was that the work stream leads felt it would be helpful to have a meeting to address common matters such as succession planning for the work streams, and to encourage developing more specific work plans.</p>		
Prehabilitation core group meeting	<p>The core group meeting is scheduled for 26/3/24. The committee recommended to proceed with SAW chairing if VC is on annual leave to keep moving forward in advance of the wider stakeholder meeting in April.</p>		
Finance	<p>WCRF have confirmed two more years of funding the partnership and supporting the core activities of the Collaboration.</p> <p>FD has requested updated financial reports for the Collaboration but it has not yet been provided. AG had delegated the request to an accountant in the relevant division.</p> <p>Karen Phekoo was previously the link between the Collaboration and UHS Finance with accountability for us, and this process has been lost since her retirement. As we aligned to the BRC, Kay Mitchell is the appropriate person to link with.</p>		
Work stream updates	<p>LWBC Maria Pufulete is leading a webinar for the Wessex Cancer Alliance on 26th March to disseminate the results from the prehabilitation services FOI request survey. This will be available online after the event.</p> <p>Toral Shah will be leading webinars on EDI matters for the work stream in collaboration with Nutritank with the first one focusing on the importance of tailoring dietary information for cultural backgrounds.</p> <p>Rachael Barlow has established a new connection with Prof Suzanne Scott from QMUL and will be developing a study on prevention of cancer for people who had a referral from suspected cancer but did not receive a diagnosis, as an opportunity for behavioural change at</p>		

	<p>this stage. They are exploring possibilities for funding with CRUK.</p> <p>The group also has an interest in patient experience and quality of life and is interested in repeating the patient survey conducted in phase one of the Collaboration's activities.</p> <p>The committee commented that if repeating this survey it should be much more targeted. Emerging features coming out of recent studies on quality of life are about disease-related fatigue as a target for many interventions, and this was not adequately captured in the original survey. SAW has been working with academics from Brighton regarding quality of life (Dame Lesley Fallowfield) and Val Jenkins (runs SHORE-C programme) and recommended bringing them into the conversation to advise on questionnaires. Cathy Bowen from Southampton was also recommended.</p> <p>An issue noted with quality of life studies was the difficulty in separating things impacted by the disease or treatment, and which are impacted by socio-economic factors and unrelated to the disease.</p> <p>It was confirmed that this survey would be kept separate from the survey about research priorities to avoid conflating issues.</p> <p>A suggestion was made to work with the charities to reach out to new patient respondents for specified groups. ECPC was recommended as a potential source of support for disseminating surveys.</p> <p>An idea was put forward of applying for a PDG as a follow on from the Macmillan guidelines to address key issues such as making the guidelines available in a patient friendly manner, pulling together the consensus work and standardisation of definitions, and research prioritisation. The Macmillan guidelines working groups has PPI in the steering group and the working groups themselves, but does not have a specific work stream on PPIE.</p> <p>Population Health</p> <p>The FORALL application [developing and testing an equitable behavioural change intervention to improve outcomes for seldom reached groups affected by breast cancer has tentatively been funded through the NIHR PDG programme, and are awaiting confirmation pending addressing queries. It has an anticipated start date for July 2024.</p>		
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	The work stream will have a joint meeting with the LWBC meeting in April to explore opportunities to collaborate in the area of secondary cancer prevention.		
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